Proceedings of the CHILD AND ADOLESCENT MENTAL HEALTH SERVICES RESEARCH PLANNING MEETING

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STATEMENT OF THE PROBLEM

Problem #1: In the past 8 years, two major reports of the National Advisory Mental Health Council have together solidified a research agenda on the effectiveness of clinical interventions for persons with severe mental illnesses. The first report, *Caring for People with Severe Mental Disorders: A National Plan of Research to Improve Services* (NIMH 1991), outlined an extensive research plan to bolster services research for adults with serious mental illnesses. The second report, *Bridging Clinical Efficacy and Service Effectiveness Research*, analyzed administrative and scientific impediments to connecting clinical treatment to service effectiveness research and provided an extensive compendium of recommendations. Together these reports have constructed a detailed blueprint for strengthening a scientific agenda for adults with serious mental illnesses.

No similar plan exists for children and adolescents with serious mental disorders. The last national plan on child and adolescent mental disorders, the *National Plan for Research on Child and Adolescent Mental Disorders*, based upon a 1989 Institute of Medicine Report, gave only slight attention to *severe and chronic* psychiatric disorders of children and to the effectiveness of treatments or services for this population.

Problem #2: System organization reforms alone do not improve children's outcomes. This is especially true for children with the most severe disorders. Yet knowledge about what goes on in the "black box" of treatment is lacking. Furthermore, curtailment of reimbursement for child mental health services is happening rapidly across the country as new health care policies are implemented, and this curtailment is likely to worsen unless substantial evidence of the effectiveness of services reaches real world practitioners. Manualized and other treatment guidelines demonstrated to be efficacious are infrequently used in practice settings. Graduate programs do not typically include coursework on the treatment-efficacy base for children. To compound the problem, most of the manualized or standardized treatment protocols have never been tested in the practice world of service delivery at all. Testing these efficacy-based treatments in service settings may require revision of traditional models of the phases of research (e.g., efficacy to effectiveness) and more tailored research strategies that are responsive to organizational variations in service settings. Adaptations are needed in research-based treatments to make them effective in practice contexts.

<u>Problem #3:</u> Major national policy reforms are now being implemented and are affecting mental health service delivery to children and their families. These reforms are hitting children with the most severe psychiatric disorders the hardest. In the past 5 years major reforms have

occurred in education services for children with serious emotional disturbances (e.g., IDEA legislation), in welfare reform, in healthcare policies (e.g., the Child Health Insurance Programs or CHIP), and in clinical practice (especially associated Medicaid managed care). The research base on treatment or service effectiveness for children with severe disorders is neither informing these reforms nor even keeping pace with them. Compounding the problem is the fact that few efforts are being made at any level of government to track the effects of these reforms on mental health services for children with psychiatric needs. The gaps are widening.

To begin to address these problems, the NIMH Child and Adolescent Services Research program convened a planning meeting earlier this year. Given recent national attention to children's mental health and the increasing visibility of policy reforms in education, health, family services, and child welfare that are affecting service delivery for the most impaired children—i.e., those with serious mental disorders—a working meeting to review the alignment or lack of alignment between the research base on children's mental health services and these policy developments was thought to be a timely first step.

Consequently this working meeting, involving 25 senior child services researchers and policy consultants in children's mental health, undertook to accomplish three tasks: (1) to identify major national policy initiatives in education, clinical care, health care, and welfare likely to affect child services; (2) to review the content, status, strength, and gaps in the current child services research portfolio; and (3) to suggest ways of aligning research on service effectiveness, clinical practice, and system reform more directly with these policy initiatives.

All participants were asked in advance to review abstracts of all currently-funded child services research grants, to read the Clinical Treatment and Services Research Report by the National Advisory Mental Health Council, and to review other reports and articles provided on the relationship between science and policy.

Brief presentations on policy reforms were made by consultants from education, welfare, clinical services and health policy organizations. Each consultant provided specific suggestions about research questions derivable from these policy trends.

All participants were asked to give a brief critique of the strengths and gaps in the child services research portfolio and to identify those research areas which were progressing cumulatively, those that had the strongest connections to policy-relevant issues, and those areas that needed re-focusing.

Three workgroups were then formed and asked to review the content and coverage of the current portfolio of studies of children's services research in the context of these policy changes. The workgroups were organized into three major scientific areas: (1) effectiveness research, including the progression from efficacy-based treatment studies to service effectiveness; (2) practice research, that is, studies on current clinical or treatment practices as delivered by real world practitioners; and (3) service system research, including studies of organization and financing. The workgroups generated reports on specific conceptual, methodological, and

infrastructure barriers to bridging research and policy, and they suggested ways of overcoming the barriers.

After the workshop, a series of conference calls with the chairs of the workgroups were held to identify areas of agreement across the three reports. These are summarized below, followed by the three workgroup reports. A complete list of all participants in the workgroups and the conference agenda is appended.

AREAS OF AGREEMENT

Infrastructure development

All of the workgroups identified the importance of continual development of the research tools for the field. Because children's services are constantly changing, ensuring that the measures, methods, and designs are adaptable and responsive to these changes is essential to the growth and quality of the research base. This foundational development is needed especially in the following areas:

- Methods development, especially as augmentations to variable-based approaches
- Measures, including child and family functioning, quality of care, quality of life, treatment adherence, treatment fidelity, risk adjustment, cultural competence.
- The relationship between diagnostic measures and functional measures.
- Training of new investigators.
- Construction of standard approaches for assessing the rules of evidence.
- Valid and brief assessment protocols.

Effectiveness of services and current practice

Two research areas were identified as having significant policy impact, but being currently underdeveloped. The first includes studies of the potential for efficacious treatments to be effective when delivered under real-world conditions. While the knowledge base on behavioral, cognitive, pharmacological, and combined treatments for some major childhood disorders is growing rapidly, studies of how best to deliver these treatments in a variety of real-world settings (including community mental health clinics, homes, schools, and pediatric settings) has not kept pace. Further, little is known about how to *sustain* effective treatments within communities, nor how to organize service delivery systems in such a way as to facilitate the maintenance of effective treatments over a long period of time.

The second area of underdeveloped research is practice research. This involves increasing understanding of current clinical practices through studies that describe specific aspects of practice that make mental health services more or less effective. This area of research is currently not represented in the child program portfolio. Studies in practice research involve observational studies of treatment in the natural environment. The focus is on the provider-consumer environment and interactions. This area of study includes questions such as what constitutes treatment as usual? What are the potent elements of the treatment process that cross different

modalities of treatment? How do therapeutic engagement, adherence, or readiness to change affect service delivery? Studies of therapeutic processes and mediators of treatment outcomes also fall within the category of practice research. Further, the question of the concordance between practice guidelines and clinical practices is relevant to practice research. Especially given the rise in the use of SSRIs and atypical neuroleptics with children, understanding current practices is important for knowing how and when they should be changed. It is important to note that the practices to be studied will need to be carefully selected. There is little to be gained from studying in detail treatment procedures that appear not to work well. This was one of the areas in previous generations of services research that has been considered to be a dead end.

Studies that are needed in the area of effective services and current community practices include the following:

- Dissemination, adoption, and maintaining sustainability of efficacy-based treatments and services in usual care settings.
- Theories and models of dissemination—what factors make a difference?
- Community variation: What aspects of communities affect, in what ways, the delivery of effective services? What are the strongest designs for answering these questions?
- Triaging mental health care: Which problems are best served by specialists and which by generalists? Are children with co-morbid problems better treated in an integrated manner or with sequential and focused attention to separate problems?
- Involving stakeholders.
- Family participation and models of family involvement in service decision-making, using family-driven algorithms for care.
- Practice guidelines and their effectiveness vis a vis differential options.
- Understanding clinical practice relative to guideline-driven practice and outcomes.
- Identifying potent contingencies for change in the practice environment.
- Developing consensus standards for what constitutes the evidence base.
- Research on the safety of multiple medications and polypharmacy; pharmacoepidemiology studies.
- Basic efficacy studies of those services that are widely used but lack a knowledge base (i.e., wrap-around, family therapies, RTC, partial hospitals).

Child service systems research

Studies of service system organization have led to major breakthroughs in knowledge about the impact of system organization on access, costs, and satisfaction with care. This scientific area is likely to become stale, however, if it is not integrally linked to clinical care. New knowledge about organizational culture and climate needs to be incorporated into system studies. Conceptual clarity through the development of systems' taxonomies is needed to reflect the changing base of children's mental health systems. Systems research could:

 Establish monitoring system to track impact of major national policies on children's mental health, including multi-site studies of the effects of managed care, CHIP, SSI, IDEA, welfare reform, or other major national policies on children's mental health.

- Conduct studies of models of organizing personnel and services for children with diverse co-morbid mental health problems.
- Construct a taxonomy of service systems.

WORKGROUP REPORTS

A. Report of the Effectiveness Research Work Group

(Workgroup leaders: Patti Chamberlain, John Weisz, Greg Clarke)

The following is a list of the issues and recommendations identified as "high priority" by the Effectiveness Research Work Group.

Formal diagnosis and alternatives

The issue: Current standardized procedures for assigning children a formal diagnosis within the *Diagnostic and Statistical Manual of Mental Disorders* are time-consuming, often frustrating for researchers and research participants, and very rarely used at all in clinical service settings. We believe research is needed that addresses the basic question of whether such formal diagnosis adds more to our understanding of children and their service needs and outcomes than alternative approaches to assessing problems and their impact. If diagnosis is found to be important, then we need research on the best ways to arrive at valid diagnoses.

<u>Recommendation</u>: Encourage, through research initiatives guidelines to review groups, increased attention to diagnosis and its alternatives. One central question should which of the following adds most to our understanding of child dysfunction, service needs, service outcomes, and prediction of long-term adjustment: diagnostic interview measures (e.g., DISC), continuous measures of problems (e.g., CBCL), measures of child functioning in life tasks (e.g., CAFAS), and/or individual functional analysis (e.g., assessment of contingencies associated with problem behavior in individual children).

Measurement technology in the child services area

The issue: A number of the constructs that many services researchers agree are important to their research are not yet well measured. Examples of such constructs include *child functioning* (e.g., in home, school, and peer contexts), *family interaction patterns, intervention processes used in service programs* (i.e., the specific procedures used during the interventions, and the child's responses to them), *provider system characteristics*, and *cultural and developmental appropriateness of interventions*. A related issue is that many of the existing measures used in clinical research are not designed for usability by clinicians and administrators, who are increasingly asked to assess quality, treatment progress, and outcomes.

<u>Recommendation</u>: Encourage, through research initiatives and guidelines to review groups, basic measure development research. The goal should be to improve the assessment armamentarium available to services researchers, and thus the ability of these researchers to achieve acceptable operational definitions of constructs critical to studies of mental health care

and its effects. Another relevant research question is which, if any, of the assessment instruments is appropriate for use in service settings by practitioners and administrators, for treatment planning, outcome tracking, and performance indexing.

Moving evidence-based treatments from research settings into service settings

<u>The issue</u>: Because of the long-standing insularity of treatment outcome research and service delivery programs, the process of bringing research-tested treatments into service settings is likely to be complex, and is an important subject for study in its own right. We need to understand the factors that make for success and failure, in efforts to bring empirically-supported interventions into practice contexts.

Recommendation: Encourage, through research initiatives and guidelines to review groups, studies designed to identify the important factors in adoption, dissemination, and effective use of evidence-based treatments. This category includes research on what causes providers, payors, and service systems to seek a revision of their current treatment approaches and/or to turn away from untested treatments. Research in this domain should include studies of what adaptations are needed in research-based treatments to make them effective in practice contexts.

Organization of care delivery systems

The issue: Although there is a growing body of evidence on treatment outcome, we lack clear evidence on the most effective ways to organize personnel and services for maximum benefit to children with diverse and often comorbid mental health problems. For example, we lack empirically-based triage guidelines for the use of primary care versus specialty care with various disorders and combinations of disorders, and we know relatively little about which problems are better served by specialists and which by generalists. We also know little about whether children with multiple problems are better treated in an integrated manner or with focused attention to separate problems, treated sequentially.

<u>Recommendation</u>: Encourage, through research initiatives guidelines to review groups, studies designed to inform organization and delivery of child mental health care. In general, the question of interest here is a variation on a theme of great historical interest in the treatment literature: What kinds of treatments, organized in what way, delivered by whom, and delivered *to* whom (i.e., the child or others in the child's environment—e.g., parents, teachers), are most effective with what kinds of children, in what kinds of families, and for what kinds of outcomes.

Family participation in treatment planning and treatment delivery

The issue: Services for children are frequently designed by "experts" and delivered in ways that do not fully incorporate family members other than the child. This may limit effectiveness of interventions, because the "experts" have time-limited involvement with the child, whereas family influence is long-term. Moreover, interventions designed and delivered without the benefit of family member involvement may not be appropriately sensitive to characteristics of the child and context that can influence whether the intervention will succeed and whether benefits will hold over time after treatment has ended.

Recommendation: Encourage, through research initiatives guidelines to review groups, research on ways of bringing parents and other family members into the processes of treatment planning, treatment delivery, and outcome assessment. This might include research comparing persistence in (versus dropping out) and outcomes of treatment procedures that do and do not emphasize family involvement, and research comparing the benefits of various approaches to incorporating the family perspective.

Alternatives to formal mental health care

<u>The issue</u>: Most research on interventions for children is focused on treatments delivered through the formal mental health care system. Omitted, in the process, are interventions and life events that are not a part of the formal system, but may nonetheless have important mental health benefits. Examples of such interventions and life events are special needs adoption, being admitted to Head Start, and home schooling.

Recommendation: Encourage, through research initiatives and guidelines to review groups, research on the impact of these alternatives to formal mental health care. Such research could profitably include tests of variations in how these alternatives are organized and carried out, and tests of ways of supporting or enhancing these alternatives—e.g., mental health outcomes for adoptive special needs children whose adoptive parents do or do not receive focused support services.

Investigator familiarity with cutting edge methodologies

The issue: Because quantitative methods are developing so quickly, it is difficult for investigators in the child mental health area to remain apprised of the state-of-the-art design and data analytic methods most appropriate to their research topics and questions. The problem grows more serious as investigators take on increasingly complex longitudinal research and as issues of cost and cost-effectiveness become critical in the field of mental health. Progress in the field is hampered as less than optimum quantitative sophistication is applied to important questions.

<u>Recommendation</u>: Initiate research seminars on such topics as hierarchical linear modeling, cost assessment, cost-effectiveness analysis, and the use and abuse of quasi-experimental designs. These should be ongoing, cyclic opportunities, ideally regional, so that travel costs could be kept manageable.

Timely (predoctoral) opportunities for investigators to enter the services field

The issue: Training support in the services area is currently focused on the post-doctoral years. Unfortunately, many promising investigators have formed their primary research identity by the time they receive their doctorate. This is particularly true of Ph.D. recipients; indeed, many of these have essentially formed their research identity from their initial year in a graduate program, when they affiliate with a particular research lab. Thus, we are missing opportunities to identify talented young investigators and attract them to services research in a timely manner, while their professional identities are being formed.

Recommendation: Enhance services research training grant programs focused on students

at the predoctoral level. Special emphasis should be placed on advertising these opportunities to graduate specialty programs that train students in relevant areas, but currently send relatively few graduates into services research—e.g., clinical psychology, special education, counseling, economics, social work.

Identification of "empirically supported treatments" for dissemination and training

The issue: An important requirement for moving empirically supported procedures into clinical service settings is that there be agreement as to *which* procedures have sufficient support to be candidates for such a transition. Currently, no such agreement exists. In harmony with an increased emphasis on "evidence-based medicine," professional groups concerned with mental health have begun identifying empirically supported procedures. However, the processes and products of different professional groups differ from one another in significant ways. For example, the "Practice Guidelines" of the American Academy of Child and Adolescent Psychiatry show quite modest overlap with the "Empirically Supported Treatments" of the Committee on Science and Practice of Division 12 (Clinical Psychology) of the American Psychological Association. The resulting differences make it unclear what treatments and procedures should actually be candidates for movement into practice settings. Even those practitioners and consumers who want to rely on scientifically-supported procedures are apt to be confused as to *which* procedures these are.

Recommendation: NIMH has the kind of cross-disciplinary influence and organizing potential to address this state of affairs. The Institute should convene a panel of experts and (at some point) stakeholders to forge an agreement on common rules of evidence, to develop a (growing) list of evidence-based treatments, and to develop plans for dissemination of information on these treatments to the service, practice, and consumer communities. In addition, the panel should generate recommendations to the Institute regarding the kinds of research most needed to facilitate awareness and effective use of these treatments in service and practice contexts.

B. Report of the Practice Research Workgroup

(Workgroup leaders: Leonard Bickman, Kelly Kelleher, Mary Evans)

The importance of knowing what goes on in the "black box" of treatment has been widely acknowledged for at least three decades. It is critical now that a new child and adolescent mental health services research agenda be constructed to focus on research that improves treatment practices. The urgent need for a portfolio of research on practice is driven by several factors. These forces include changes in the practice world as well as recent findings of research supported by the NIMH.

The Practice World

- New emphasis on the importance of client outcomes.
- Increased need for accountability.
- Emergence of managed care.
- Manualized and other treatment guidelines shown to be efficacious are infrequently used.

Findings from NIMH Research

- Major changes occurring in the practice world (i.e., system changes) have not been shown to affect client outcomes.
- Treatment protocols, guidelines, and lists of efficacious treatments have been developed but not tested in the practice world.
- Efficacy research shows that psychotherapy can produce significant client outcomes but usual care does not appear to be effective.
- Increasing awareness that we are unable to describe treatment in the practice world.

We have already seen the curtailment of reimbursement for child mental health services and the situation is likely to become worse without substantial evidence of the effectiveness of usual services. There is worldwide demand to show value for all human services. We need to describe better the nature of routine treatment, identify strategies to improve treatment, and discover and apply approaches to changing treatments in the community.

At present we know little about what goes on in the real world of treatment, except gross service utilization data such as location, charges, and modality of services. Practice research is needed to describe treatment in the natural environment so that we can design more effective and feasible treatments. From a research perspective, information about "treatment as usual" is necessary to serve as a comparison for innovative treatment. Practice research will provide information that is necessary to produce better clinical outcomes.

This area includes such topics as quality of care and treatment processes, such as intake, assessment, treatment planning, delivery of treatment, engagement, supervision, adherence, and follow-up. It also includes the in-depth description of treatment. It includes investigation of therapeutic processes that appear to be mediators of treatment outcomes, such as therapeutic alliance. It encompasses the study of the effectiveness of guidelines and parameters of practice and other methods to encourage the adoption of effective treatments. Practice research can also relate to the organizational structure and climate of practice organizations, with the goal of improving client outcomes. Practice research may focus on all types of services provided by individuals who attempt to improve the mental health of children through the delivery of a service. Thus, treatments delivered by various professionals and non-professionals, such as peers or parents, should be included in this area. Finally, practice research focuses on approaches that are effective in changing ineffective services in the community.

Effectiveness and Systems Research

Practice research shares a border with effectiveness research. We see effectiveness research, where the clinical staff delivers the intervention, as research that can fall into either category of research. Intervention research focuses solely on interventions, but practice research considers descriptions of practice as well as interventions introduced into the natural world setting. Moreover, practice research must be sensitive to the context in which an intervention is introduced. It does not assume that interventions or treatments are universally portable.

Practice research differs from system research in its focus on the provider-consumer environment and interactions. System research focuses on system level factors such as system integration, large-scale system organizational issues, and financing of systems of care. However, practice research also shares a border with systems research. For example, practice research may study similar methods of change such as legislative action but it would focus on the mental health provider or the client –provider relationship.

Impediments

Impediments to the development of this field fall into three general categories: (1) methodological, (2) structural, and (3) conceptual.

1. <u>Methodological Impediments</u>

- Limited measures of process and outcomes in practice settings.
- Limited measures to describe treatment.
- Limited measures of the practice environment.
- Limited measures of clinician characteristics competency, attitudes, background.
- Limited measures to use outside of usual psychotherapy sessions, that is, in settings such as group homes, camps and foster care.

2. Structural –Organizational Impediments

- Practice organization resistance to change, or inertia.
- Limited resources to support change and the study of change.
- Lack of a "learning organization" perspective in the practice environment.
- Knowledge about how to establish relationships with practice environments such as clinics, managed care organizations, parent groups and professional associations.
- Lack of good collaborative efforts of federal agencies. Lack of inter-agency agreement on funding doesn't allow good study of services for co-morbid clients.
- Threat to the practice environment from researchers about uncovering deficiencies.
- Threats to researchers about the potential lack of cooperation from service organization and sabotage of research programs.
- Lack of good funding strategies to assist collaborating partners.
- Need for careful consideration in assignment of practice research proposals to appropriate review groups.
- Insufficient NIMH staff to support new field of practice research. It will require dedicated staff and on-going support.
- Difficulty in accessing special populations.
- Potential research participants, especially staff, have little incentive to participate in practice research.
- Lack of set-aside funds to fund this new practice area of research.
- Studies may take longer and cost more than easier-to-implement efficacy studies.
- Lack of standardized and in-place measures of process and outcomes in service delivery organization that would greatly reduce the cost of practice research.

3. Conceptual Impediments

- Insufficient conceptual development of the field practice research. Where does practice research fit? What are the theories of practice research? What are the special methods and training needed?
- Cultural diversity and heterogeneity of populations served.
- Lack of standardization of treatment and treatment planning; especially across different sectors makes it difficult to conceptualize treatment.

Major content areas missing

This new and emerging area of services research lacks substantial representation in the current NIMH child portfolio. A small number of studies provide incidental description of some elements of practice in usual care; however, none of the NIMH portfolio in child and adolescent mental health services research was designed to capture the critical interactions among structural and process features of practice at the micro level, and the delivery of treatment to families, patients, and communities. Future studies, in addition to describing such elements, should be based on theories of practice developed from organizational and behavioral research, with the aim of identifying areas for improving outcomes. In short, models need to be to developed that suggest how to improve practice locally through the identification of essential elements of treatment and the necessary structure and process to support that treatment.

Strengths of the program area

The biggest strength of this area is the recognition that we lack critical knowledge about practice that is necessary to improve the mental health of children in this country. Knowledge in this area is necessary to improve practice and thus provide more cost-effective services. We have already learned that publications in scholarly journals do not result in changes in practice. Moreover, typical continuing education approaches seem to have little impact. Research is needed to learn how to translate efficacy research procedures into practice. Collaboration is a major goal of NIMH (e.g., PAL program). Practice research has the potential help transform service delivery organizations into learning organizations.

Recommended specific research strategies.

- 1. <u>Research on interventions in the practice environment</u>. Interventions to improve practice can be categorized in several ways. These interventions have not been subject to testing in the practice environment. Some of these categories of potential interventions include:
 - *Provider selection* identifying the characteristics of providers that are related to better clinical outcomes, e.g., selection for empathetic abilities.
 - Manualized treatments the application and appropriate modification of efficacious, disorder-specific treatment manuals to the practice environment, e.g., treatment for anxiety.
 - *Practice guidelines* the use of more general approaches to treatment that has been proposed to produce better clinical outcomes, e.g., guidelines for the identification and treatment of ADHD.
 - Generic mediators of treatment outcomes the identification and modification of mediators of treatment outcomes that are common to most treatment, e.g., therapeutic alliance, readiness to change, engagement in treatment.

- *Matching* the matching of client and provider characteristics to determine which produce the best outcomes, e.g., preference of strategies of treatment.
- Organizational climate and structure Alteration of the organization that results in improved outcomes, e.g., improving organizational climate or altering practice structure to enhance continuity and adherence.
- *Generic treatment processes* Improvement in generic treatment processes that may be related to clinical outcomes, e.g., better treatment planning, better supervision.
- *Payment* providing payment for appropriate and effective treatment and no payment for the provision of ineffective treatments. Payment may also be based on outcomes.
- *CQI* Continuous quality improvement has been proposed as a general approach to improving outcomes. This approach, while having widespread support in the health sector, has not been examined in mental health.
- 2. <u>Measurement development and application</u>. Programs of research that would develop measures that can be used in the practice world that are valid and practical to use.
 - Child and family outcomes symptoms, functioning, family functioning
 - Mediators of treatment therapeutic alliance
 - Fidelity of treatment
 - Descriptions of treatment
 - Descriptions of the practice environment
- 3. <u>Developing collaboration among researchers, providers and consumers.</u>
 - Consideration of how to establish and maintain relationships with practice environments. Small grants are needed to facilitate training of research partners.
 - The establishment of practice networks involving several professions. While there are some practice networks established, they do not have stable support and neither do they cooperate with each other. Infrastructure support would provide some stability, and more importantly, greater access to researchers.
- 4. Research on the effectiveness of training, certification and accreditation. These are commonly used and accepted mechanisms for assuring high quality and effective services. However, there is no substantial body of research that shows that these approaches improve outcomes for consumers. Research is needed on how to improve the effectiveness of these techniques.
- 5. Research on cultural competence in practice environments. Support is needed for the development of culturally competent measures, including workshops for researchers, support for minority researchers, initiatives/incentives to examine minority populations related to practice, and incentives for investigators to disseminate efficacious initiatives to different communities. Increase funding for minority investigators and initiate funding for collaborators who are not researchers. All stakeholders need to be represented in this effort.
- 6. <u>Collaborative research among agencies</u>. More cooperative efforts between NIMH and other relevant agencies would benefit practice research. In particular, cooperation between NIMH and

CMHS would be especially beneficial. However, we recommend that any such efforts not limit NIMH to only funding research at specific sites funded by CMHS.

- 7. <u>Prioritization for practice research</u>. Since this is a new area of research that should have a high priority, it is important for it to be "jump started." A critical number of existing projects are needed in this area to establish its presence. One way to accomplish this is to issue a special initiatives in this area to support 8-10 projects.
- 8. <u>Additional NIMH staff</u> to assist with program development, grant review, preparation of RFAs, and collaborative work across federal agencies, etc.
- 9. <u>Service projects focused on late adolescence/young adulthood</u>. The field needs to have a better understanding of the service needs and effective interventions to support the educational, work, and personal goals of this age group.
- 10. Focused attention on the review process for practice research. The current plans for reorganization of NIMH review call for mental health services review at NIMH to be divided into two broad areas: intervention research and service system research. The NAMC Report on Bridging Clinical Treatments and Service Effectiveness identifies practice research as a third area of research that needs NIMH's attention. As such, its interests may not be well represented in the two defined review areas. The Practice Workgroup proposes either a separate review process or an *ad hoc* process as a temporary solution until the composition of the review committees, their mandate, and the scope of proposals in this area become clear.

C. Report of the Systems Research Workgroup

(Workgroup leaders: Sally Horwitz, Barbara Burns, David Shern)

Strengths of the program

The Committee identified that research on barriers is well covered across multiple services systems. We suggest that researchers and staff from different federal agencies working in this area be brought together for a workgroup to discuss the status of work being done in the different sectors, and how this work can be best brought to bare on the problems facing child mental health services. The Committee also identified a strength within NIMH that could be applied to the systems portfolio. We believe that the collaborations developed by NIMH (eg., NCHS, ACF, NIJ, CMHS) with other agencies are critical to the systems research area. We believe NIMH is poised to capitalize on these relationships and needs to bring together representatives from juvenile justice, pediatrics, and child welfare to discuss possible cross agency systems research initiatives.

Important, unaddressed issues in the program area

Using only data from the current portfolio, the Committee identified a number of unaddressed issues. Many of these issues are critical given the current health care climate, including:

1. The impact of various legislative efforts including CHIP, IDEA, Welfare Reform

(including SSI)

- 2. The impact of various financing initiatives, such as managed Medicaid
 - Research on risk adjustment.
 - Impact of parity and universal coverage on child health/mental health outcomes.
 - Impact of variations of a single purchaser (pooled funding) for children's services on the access to, structure of, and outcomes of after care.
- 3. A taxonomy of services systems
 - Develop a theory of organizational impact integrating various system levels and integrating the concepts of culture and climate. Develop a typology of systems linked to this theory.
 - Link systems taxonomy to changes in practice (e.g., clinician guidelines) and subsequently to changes in child and family outcomes.
 - Identify the systems characteristics that encourage the adoption of innovation, such as use of practice guidelines, quality improvement procedures, evidence-based therapies/programs/procedures.
 - Identify characteristics of organizations and financing arrangements that improve access to care for high-need children and youth.
- 4. Systems sectors delivery issues
 - Where should children's mental health services be based (eg., schools, primary health care, specialty mental health) for addressing specific disorders for children of different ages?
 - How do school-based health and mental health services programs relate to and interface with other mental health services?
 - How do personnel involved in juvenile justice (police, judges, probation officers) handle decisions about children and adolescents with mental disorders?
- 5. Process of Care
 - Relationship of regulations to practice and subsequently to outcomes.
 - Team approaches to service delivery teams including roles and functioning of team members and the impact on youth functioning.
- 6. Development and evolution of family organizations and the role family groups should play in the emerging systems of care.

Impediments to Progress

Our team identified several impediments to progress, including:

- 1. Few mechanisms for NIMH to join with other institutes or agencies for systems collaborations
- 2. Rigidity of academic disciplines and academic settings/cultures (eg., the failure of academic culture to support and legitimate interdisciplinary fields of study).
- 3. Shortage of systems theorists.
- 4. Challenges in working with systems at any level include conflicting agendas among providers and between providers and researchers, shortage of resources, turnover, lack of trust.
- 5. Levels of complexity of any one system (e.g., mental health) and the intricate web of relationships within and among systems.

- 6. Lack of a mechanism for matching interventions in public mental health settings with researchers.
- 7. Need to identify mechanisms that allow incorporation of and maximize collaboration among various stakeholders.
- 8. Few occasions for exchange of information in a functional format.

Specific Research Tools or Strategies

We identified 4 critical areas:

- 1. A systems taxonomy and methodology for categorizing specific systems
- 2. Outcome measures particularly ones that represent meaningful measures of functioning and that relate to alternative resource use (level of care/intensity of services).
- 3. Strategies to study multiple linked systems.
- 4. A way of brokering linkages (through out-sourcing and tied-to funding) of sites and researchers.

Specific Action Steps

We identified 5 specific activities to revitalize this area of research:

- 1. We recommend that any services systems initiative should encourage the use of, but not be limited to, the CMHS sites. One announcement should be a joint CMHS/NIMH endeavor where CMHS provides the second generation services dollars and NIMH provides the research dollars. The joint endeavor should be replicated with other agencies that serve children with behavioral and emotional problems, such as ACYF, NIJ and HRSA.
- 2. Service systems announcements to encourage multisite projects and to use the entire range of investigator-initiated mechanisms. To promote the development of mature multi-site research endeavors, we expect that it will be necessary to fund small planning grants and subsequently fund one or two large multi-site studies. This process assumes that any announcement will be sufficiently detailed in order for investigators to respond.
- 3. Consultation from system research experts from different sectors. The results of this process can be posted on the NIMH web site, comments can be solicited, and the announcement then finalized. This process should be instituted quickly.
- 4. To align the research base on service systems with policy developments, two specific research initiatives are especially needed now. One should focus on systems receptivity to the adoption and sustainability of innovative practices; and the second should focus on the impact of managed care initiatives on child mental health. We conceive of these as broadbased, multifaceted research agendas covering the areas of need outlined earlier in this document.
- 5. Joint meetings between NIMH staff and systems staff from NIDA, NIAAA, etc. to review their announcements and identify areas of mutual interest. Members of this committee could assist in the preparation of an analysis of the various announcements prior to that meeting. We also suggest that a personal service contract be issued for the development of the systems taxonomy. We envision this as support for a small group of systems experts with a clear time line and product.

Agenda

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES RESEARCH PLANNING MEETING

January 20-22, 1999 Belmont Center Elkridge, MD

Wednesday, January 20

5:00-8:00 Reception and dinner

Thursday, January 21

8:30 am **Overview of Child Services Research Program Priorities**

Kimberly Hoagwood, Ph.D., NIMH Grayson Norquist, M.D., NIMH

9:00 **Policy Panel**: What kinds of national policies affecting children's mental health are likely to be enacted in the next 5 years?

Clinical care: Mary Jane England, M.D., Washington Business Group on

Health; Christina Crow, Judge Baker Children's Center

Legislative initiatives in welfare, health and justice: Mary Lee Allen,

Children's Defense Fund

Family issues: Elaine Slaton, Federation of Families Education issues: Steven Forness, Ed.D., UCLA Managed care: Kelly Kelleher, M.D., U Pittsburgh Child service systems: Michael English, J.D., CMHS

| 10:45 | Discussion |
|-------|--|
| 11:15 | Break |
| 11:30 | Science and policyA two-way exchange. Limits and opportunities |
| | Commentary and Discussion Leaders: Peter S. Jensen, M.D., NIMH |
| | Leonard Bickman. Ph.D., Vanderbilt University |
| 12:30 | Lunch |
| 1:45 | 5 minute reactions by each participant to the coverage, content, and emphasis of |
| | the child research portfolio: Strengths, gaps, cumulative progress, connections to policy. |
| 3:00 | Discussion: How do the content, coverage, and emphases relate to anticipated |
| | policy changes? How can the research be better aligned with expected policies? |
| 3:45 | Break |
| 4:00 | Working groups |

Participants will meet in small groups (see attached assignment sheet) to identify strengths and gaps in efficacy and effectiveness research (group A), practice research (group B), and systems research (group C). Groups are expected to identify major methodological, conceptual, or practical barriers in aligning the science of these areas with policy, and make specific recommendations for

development of these fields of study. End of day one Dinner

5:30

6:30

Friday, January 22

| 8:30 am | Working groups continue to work |
|---------|--|
| 10:00 | Reconvene: Summaries of working group recommendations |
| 10:45 | Discussion: Integration of science recommendations with policy |
| 11:30 | Final recommendations and wrap-up |
| 12:00 | Lunch |

List of Participants CHILD AND ADOLESCENT MENTAL HEALTH SERVICES RESEARCH PLANNING MEETING

January 20-22, 1999 Belmont Center Elkridge, MD

| Mary Lee Allan Children's Defense Fund | Mary Evans, Ph.D. University of South Florida | John March, M.D. Duke University |
|--|---|---|
| Marc Atkins, Ph.D. University of Illinois | Steven Forness, Ed.D. UCLA | Mary McKay, Ph.D. Columbia University |
| Len Bickman, Ph.D. Vanderbilt University | Charles Glisson, Ph.D. University of Tennessee | Jeannie Miranda, Ph.D. Georgetown University |
| Barbara Burns, Ph.D. Duke University | Malcolm Gordon, Ph.D. NIMH | Grayson Norquist, M.D. NIMH |
| Gerald Calderone, Ph.D. | Scott Henggeler, Ph.D. | Agnes Rupp, Ph.D. NIMH |
| NIMH Patti Chamberlain, Ph.D. | Medical University of South Carolina | David Shern, Ph.D. University of South Florida |
| Oregon Social Learning Center | Kimberly Hoagwood, Ph.D. NIMH | Elaine Slaton Federation of Families |
| Gregory Clarke, Ph.D. Kaiser Permanente | Sally Horwitz, Ph.D. Yale University | Anne Riley, Ph.D. |
| Portland, OR Christina Crow, Ph.D. | Peter Jensen, M.D. NIMH | Johns Hopkins University Linda Teplin, Ph.D. |
| Judge Baker Children's Center | Kelly Kelleher, M.D. | Northwestern University |
| Mary Jane England, M.D. Washington Business Group | University of Pittsburgh John Landsverk, Ph.D. | John Weisz, Ph.D. UCLA |
| on Health Michael English, J.D. | Children's Hospital San Diego | |
| Center for Mental Health Services | Phil Leaf, Ph.D. Johns Hopkins University | |